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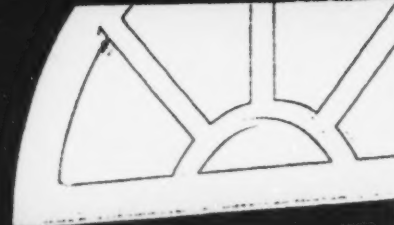
ABSTRACT

This booklet on money management and financial resources is targeted to parents of a child under the age of 18 who has a disability. The guide outlines step-by-step financial management techniques and provides information on resources. Chapter 1 focuses on the need for parents to organize financial information. Parents are urged to keep their records in one place, make a spending plan, and learn ways to manage debt. Worksheets are provided for developing a spending plan. Chapter 2 discusses health, life, and disability insurance policies. Different types of medical coverage are explained and a chart is provided to help parents analyze their policies and learn about their benefits. Strategies for working with health care providers are given. This chapter also reviews rights under the Family and Medical Leave Act and the Americans with Disabilities Act, and provides information on lifetime maximums, the Consolidated Omnibus Budget Reconciliation Act (COBRA), and federal and state insurance programs. The issues of medial privacy are also discussed. Chapter 3 addresses planning for the future, retirement and savings programs, social security, employer plans, self-funded retirement plans, estate planning, the special needs trust, and conservatorship. The last chapter lists parent organizations and resource organizations. (CR)

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A FINANCIAL RESOURCE BOOK FOR PARENTS OF CHILDREN WITH DISABILITIES



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POSSIBILITIES:

A FINANCIAL
RESOURCE BOOK FOR
PARENTS OF
CHILDREN WITH
DISABILITIES



NATIONAL ENDOWMENT FOR
FINANCIAL EDUCATION

Partnering for Financial Well-Being



This booklet is intended to provide general financial information; it is not intended to substitute for, nor supersede, professional or legal advice. The specific needs of every disability or life circumstance have not been covered. The best course of action must be based on individual circumstances.

Note: The content areas in this material are believed to be current as of this printing, but, over time, legislative and regulatory changes, as well as new developments, may date this material.

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TABLE OF CONTENTS

LETTER TO PARENTS	2
CHAPTER 1: ORGANIZING	4
Keep Your Records in One Place	6
Make a Spending Plan	10
Your Goals	10
Step 1: List Your Monthly Income	12
Step 2: List Your Monthly Expenses	13
Step 3: Compare Income and Expenses	15
Step 4: Find Resources and Make Changes	15
Manage Debt	16
Get Help	16
About Bankruptcy, Foreclosure, and Repossession	17
CHAPTER 2: INSURANCE	20
Your Medical Policy	20
Things to Think About	22
Making Your Policy Work for Your Child	26
Lifetime Maximums	29
Inadequate or No Medical Coverage	31
Life Insurance	35
Social Security and Life Insurance	35
Calculate Your Life Insurance Needs	35
Your Disability Insurance	36
CHAPTER 3: PLANNING YOUR FUTURE AND YOUR CHILD'S FUTURE	38
Retirement and Savings Programs	39
Social Security	39
Employer Plans	40
Self-Funded Retirement Plans	42
Your Long-Term Care	43
Estate Planning for Your Family	44
An Overview of Estate Planning	45
The Special Needs Trust	46
Fund a Special Needs Trust	48
Conservatorship (Guardianship)	50
CHAPTER 4: RESOURCES	52
Parent Organizations	52
Comprehensive Information/Referral Centers	54
Find a Financial Planner or Lawyer	55
Your Rights as a Caregiver	55
Insurance	55
Government Programs	56
Cover "Associated" Costs	57
IN CLOSING	58

Dear Parent,

When a child is diagnosed with a disability, it can be overwhelming—both emotionally and financially. Suddenly, all your expectations and plans for your child's future must be changed, or at least modified. When looking into the future, even the most stable of families may find themselves in a very tough spot regarding money. This may happen at a time when you are simply not ready to think about practical matters. Considering financial issues at this time is extremely difficult, but you can create order and maintain control over your finances, even as you raise your child.

Raising your child while taking care of practical matters *will* take effort on your part. But you are not alone. There are resources to help you. Throughout this country there is a growing network of parents helping parents. These individuals can talk to you from personal experience about the feelings you have, the problems you face, and the solutions they have found. Numerous groups, agencies, and organizations—both public and private—are here to provide you with emotional support and practical help.

That is why the Parent Advocacy Coalition for Educational Rights (PACER Center) and the National Endowment for Financial Education® (NEFE®) have collaborated to publish this booklet. This is a simple, straightforward guide to money management and financial resources targeted to parents of a child, under the age of 18, who has a disability. Its purpose is to help you make sense out of information that may seem confusing and sometimes contradictory. This guide outlines step-by-step financial management techniques and provides clear information and leads on resources. These financial management techniques can help you, not just in times of crisis, but for the rest of your life.

Before we start, let's take a look at some facts that every parent of a child with a disability needs to know:

△ Many financial issues surround disabilities. In general, health care costs are high and they continue to rise. If a child needs special health care, medications, or equipment, health care costs will be much higher. There may be a number of disability-related expenses that are *not* medical that need to be considered—assistive technology, transportation, assistance with activities of daily living, respite care for family members, special home care for the child, home renovations, loss of work time, and more.

△ Insurance plans may cover health care costs associated with disabilities. If an insurance policy does cover these costs, there is usually a co-payment, deductibles, and/or co-insurance payments that must be met.

These cumulative payments can run into many thousands of dollars. Additionally, many policies have a maximum lifetime limit for benefits, and perhaps a lower one for any one illness or injury. You must know what your policy does and does not cover in order to get the maximum benefit from it.

△ Eligibility for government programs such as Medicaid and Supplemental Security Income is based on need as well as disability. It is important to know how to manage your money to provide for the basic costs of raising your child, without eliminating the possibility of eligibility for government programs. "Need" is strictly defined, so it is important to keep track of information that will document need. Establishing need can take time, but will be well worth the effort. Documentation is important not only to establish eligibility and manage money, but also to support an accounting of payment received from the government if necessary.

The best way you can be prepared is to *organize* the information you need. This is crucial to easing your situation. With patience, the right information, and a positive attitude, you can obtain the help your child and your family need. Of course, you can't accomplish everything at once. So don't expect that of yourself. It's really a matter of taking things one step at a time.

We invite you to begin.



CHAPTER 1:

Organizing

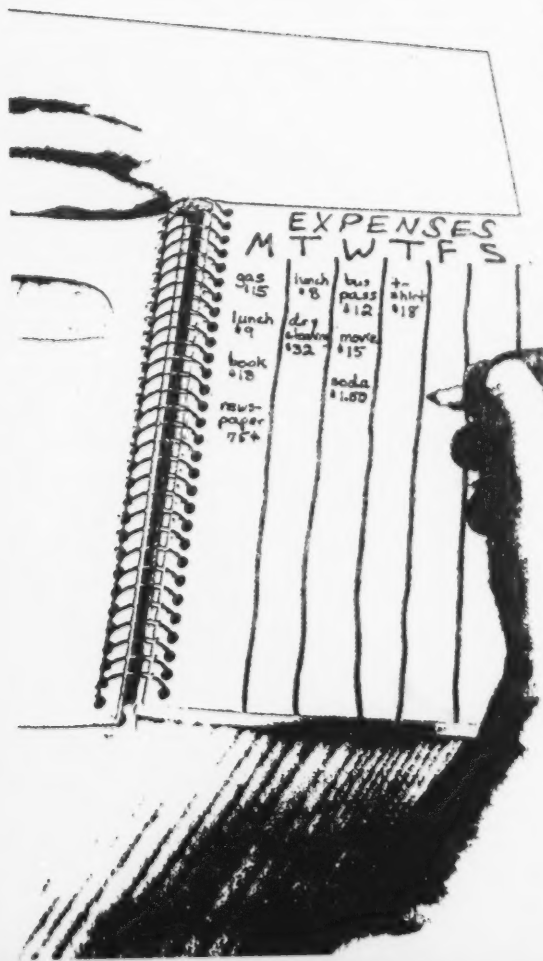
In times of emotional stress, the financial implications of a disability are often "put on the back burner." This is understandable, and even sometimes necessary, to meet all the requirements of raising a child with a disability. Raising your child and making sure all of his or her needs are being met is your first priority.

But the financial implications of your child's special needs must be addressed too. The ability to organize is one of the most important and practical skills a family needs. By organizing your income and expenses, insurance policies, medical bills, and other disability-related bills, you can stay on top of your financial obligations. Too often, families don't even realize they are in financial trouble because they have become lost in the mounds of paperwork resulting from disability-related expenses.

So, the first step of this journey is to organize your family's finances. This section provides simple, how-to information on three major steps toward financial organization:

1. Keep your records in one place
2. Make a spending plan
3. Learn ways to manage debt

In this chapter, we ask you to organize your files, which can be a daunting task in itself. You will need to calculate your monthly income and expenses. We suggest you keep a telephone log and a spending diary. These activities can help you stay organized. Don't feel that you need to do all these activities at once. Some will be necessary for you, while others won't be relevant to your circumstances. Take what is useful for you and use it to reach your goal—which is to manage the financial consequences of your child's disability-related needs and your family's overall financial goals.



ONE FAMILY'S APPROACH TO PAPERWORK



When we first brought our daughter, Ann, home from the hospital, I felt overwhelmed. Ann was so tiny and needed all my attention. Here we were—faced with heaps of junk mail, unpaid household bills, insurance claim forms, and more. On top of these, there were medical bills from doctors, labs, and the hospital. I didn't understand the charges and I didn't know what our insurance covered.

At first I was tempted to shove it all aside and think about it later. Instead, I enlisted my husband's help. He threw out the junk mail and sorted everything else into rough piles. In the days that followed, I spent a little time each day setting up a filing system. When I had finished, I felt a sense of satisfaction and relief.

We now use that system all the time. It helps in many ways. We know how much we owe and when the payments are due. We have information on hand if we need to appeal an insurance decision. Most of all, we've been able to prove my daughter's eligibility for benefits.

Keep Your Records In One Place

With your records at your fingertips, you are better able to act as an advocate for your child. Your records will help you save time and encourage faster action from your insurance company and from government agencies.

You may find that you have accumulated many bills, explanations of insurance and Social Security claims, as well as other papers. Begin by setting aside about an hour each day to make sense of the pile. (You will be surprised at how rapidly you can conquer paperwork, once you break the project down into manageable tasks and time frames.)

Obtain an inexpensive file cabinet, box, or storage container and some file folders. Label the file folders and alphabetize them for ready reference. Use the following file categories as a starting place, altering them and adding your own to fit your particular needs.

△ **Bill payments.** As bills come in to be paid, place them in this file. Mark on a calendar when each bill is due. Each time you are paid, or receive income from any source, make payments on the bills that are due. If you cannot make a full payment, make a partial payment and send it along with a letter explaining your circumstances. Making a partial payment by the due date can help protect your credit record. File the bills that have been paid according to the month they were paid. Keep paid bills as part of your permanent records.

△ **Checking account records.** File canceled checks and monthly bank statements here. In the future, you may need these records to prove you have made certain payments. Keep canceled checks indefinitely.

△ **Cost-of-living expenses.** You may be required to establish financial need by outlining your family's normal expenses, such as rent, utilities, food, and clothing. File records of what you usually pay for these cost-of-living items. Keep this as up to date and accurate as possible.

△ **Income records.** Include paycheck stubs, correspondence from private and government funding sources stating how much you receive, and statements saying how much you receive in alimony or child support, if any. If you receive a gift of money, make a note of it and put it in this file. If you have income from savings or investments, record these amounts in this file. You will need income records to make a spending plan for your family and possibly to prove eligibility for various programs. You should keep these records indefinitely.

△ **Insurance records.** At this time, your medical policy is one of the most important documents you own. Keep your policy here so that it is readily available. Be aware that if the "policy" you have is through an employer, the

SIMPLE PLEASURES

FOR THE WHOLE FAMILY

- ▲ Check local newspapers for free community events (concerts, fairs, museums, etc.).
- ▲ Fly a kite.
- ▲ Create a puppet show.



FINDING THE SPENDING LEAKS

Over time, spending small amounts can add up to a great deal of money. For example, going out to lunch every workday could easily cost \$7 a day, or about \$1,750 a year (50 weeks x 5 days a week x \$7 a day). Specialty coffee at \$3 a day adds up to more than \$700 a year. To find your own spending leaks, make a list of small but frequent purchases you make to see how much these "minor" purchases cost you over a year. The most effective method is to keep track of every expense, each day, for two to three months. This is not easy, but it helps you think about how you spend your money. With this record, you can account for how you spent your money and see that it does not merely disappear. The advantage of keeping a record is that you learn to recognize how you are spending money and you develop a habit of being aware of each purchase.

employer maintains the entire policy and you merely have a summary. Also, keep copies of your life, disability, long-term care, homeowners or renters, and car insurance policies. Keep all correspondence concerning your insurance and file it by date. If you have a safe-deposit box, keep a list of policy numbers and companies there as well.

△ **Loan and credit records/receipts.** File loan agreements and payments. Be sure to include mortgage and credit card statements. Your credit card statements may be important as proof of payment for reimbursable medical equipment, assistive technology, and other things. Keep the agreements and payment records until your loan is paid in full. Then, you need to keep the title of ownership and the document that states your debt has been paid in full.

△ **Receipts and warranties.** Receipts and warranties are especially important for major purchases that support your child's life or increase your child's quality of life. You may need your receipts for possible reimbursements. Many of the costs are tax-deductible. Keep this information for as long as you have the item you purchased.

△ **Social Security.** Keep records of all payments received and sent, copies of all correspondence received and sent, and notes of all telephone and in-person conversations with Social Security agents. Keep these records forever. There is no expiration date for when the government can check on Social Security overpayments.

△ **Special expenses related to your child's disability.** Expenses related to your child's disability can often be deducted for tax purposes and used to determine your child's Social Security eligibility. Be sure to keep and file receipts for items such as transportation to and from treatment, parking while at treatment, lodging (if you must be away from home for treatment), meals away from home for family members during your child's hospitalization, child care costs for siblings, and tutoring for your child with a disability while he or she is in the hospital. After the child leaves the hospital, there may be special diets, medical equipment, assistance with activities of daily living, special home care for your child, utility costs, and home renovations. There may be other items that you can add to this list. It is best to consult a financial advisor



regarding writing off expenses for income tax purposes. Keep information related to these expenses indefinitely.

△ **Telephone logs, home visits, e-mail messages, and faxes.** In this folder, store information about all communications that you have regarding your child with a disability. For telephone conversations or home visits concerning your child's disability, keep a simple spiral-bound notebook by the telephone or with your files. Record the following information: date and time of the call or conversation; name, title, and telephone number of the person with whom you talked; reason for conversation; and the outcome of the conversation. For e-mails, you may want to print a hard copy of the electronic message for your files. File a copy of any fax you receive or send.

Keeping a log of your communications is important for (1) recalling important information that is given to you, such as a physician's interpretations of medical results; (2) remembering information that you gave, for instance, to a health professional or to an agent of the Social Security Administration; and (3) reconstructing the sequence of events in case you need to document your actions. Keep this information indefinitely.



Make a Spending Plan

When family finances are strained, you may believe that you need to give up your lifestyle completely. It is true that you may need to make some real sacrifices. But, it is also true that some simple adjustments in spending habits can help you save some of the money you need.

Did you know that the average family loses 30 cents of each dollar (or 30 percent of their money) through careless spending? For example, if you earn \$600 a week, your spending habits could be robbing you of \$180. But if you stop this loss, it's like giving yourself a 30 percent bonus or pay increase.

Your Goals

It's difficult to think about long-term goals when you first learn of your child's disability. Your main goal may be to meet your immediate financial obligations and stay out of major debt. But you may have other goals, too, of which

"There are many programs to help meet expenses, but they are not always well-publicized. This means you have to use all the 'know-how' and 'stick-to-it-iveness' you can muster. You really have to dig to find the help your child needs!"

—Mindy Cheney, mother of Carol Ann, age 19



you don't want to lose sight, such as saving for your child's education, investing for your retirement, and establishing an estate for your heirs.

To meet these goals, you need a basic plan called a *spending plan*. There are four steps to making a spending plan:

1. List your income and your expenses
2. Compare your income and expenses
3. Set goals
4. List your resources and set priorities to achieve your goals

For your spending plan to work, it is important to accurately estimate both your monthly income and expenses. Set a little time aside to complete the spending plan worksheet we have provided. If you have a computer, a household financial management software program can be very helpful.

On the income side, in addition to your regular income, list all the funding you can reasonably expect to receive related to your child's disability, such as medical reimbursements from your primary insurance provider, government benefits, and gifts from community, civic, and religious organizations.

On the expense side, it helps to obtain expert advice about the long-term costs related to your child's disability. Talk with other parents whose children are older and have disabilities similar to those of your child. Ask your doctor and other medical providers for a projection of costs. There may be associated expenses related to your child's disability. For example, if a child will outgrow an assistive device in a few years, consider the cost of replacing this item. Talk to other parents and your social service caseworker (if you have one)—they may be able to help you anticipate expenses. Other parents may be able to suggest less expensive but equally effective alternatives to buying new items as your child outgrows the old ones. If you need further assistance, contact your state's parent center. PACER Center, listed in Chapter 4: Resources, can assist you with finding your state's parent center.



SIMPLE PLEASURES

FOR THE WHOLE FAMILY

- ▲ Get involved in social activities (volunteer work, religious organization, school, community service, etc.).
- ▲ Take an outdoor adventure trip. (Some organizations provide full accessibility for all people along with funding sources. One source is the Wilderness Inquiry Outdoor Adventure. You can inquire at 800 728 0719 (toll free) or at www.wildernessinquiry.org.)

#

STEP 2: List Your Monthly Expenses

Once you've determined your income, take a look at your expenses. For expenses paid only once or twice a year, or for one-time-only expenses, determine the number of months it will take to pay off the item. Then divide the cost of the item or expense by the number of months. List this amount on the worksheet below. If you buy an assistive device that costs \$6,000 (including interest), for example, and you believe you can pay that amount in 60 months, list \$100 (\$6,000 divided by 60 = \$100) as the monthly amount below. For bills that vary each month, such as your phone bill, use averages.

Expenditures	Per Month
House payment or rent	\$ _____
Homeowners or renters insurance premiums	\$ _____
Health insurance premiums	\$ _____
Life insurance premiums	\$ _____
Natural gas or heating fuel	\$ _____
Electricity	\$ _____
Water	\$ _____
Telephone (local and long distance, plus any special services)	\$ _____
Computer and Internet services	\$ _____
Groceries	\$ _____
Meals eaten out	\$ _____
Transportation (public transportation, car payments, gasoline, insurance, maintenance, repairs, etc.)	\$ _____
Dental bills	\$ _____
Pet care	\$ _____
Union and professional organization dues	\$ _____
Clothing costs	\$ _____
Tithing or charitable donations	\$ _____
Loan payment	\$ _____
Credit card payment	\$ _____
Personal (toiletries, allowances, etc.)	\$ _____
Entertainment	\$ _____
Miscellaneous (cable TV, newspapers, magazines, classes, etc.)	\$ _____

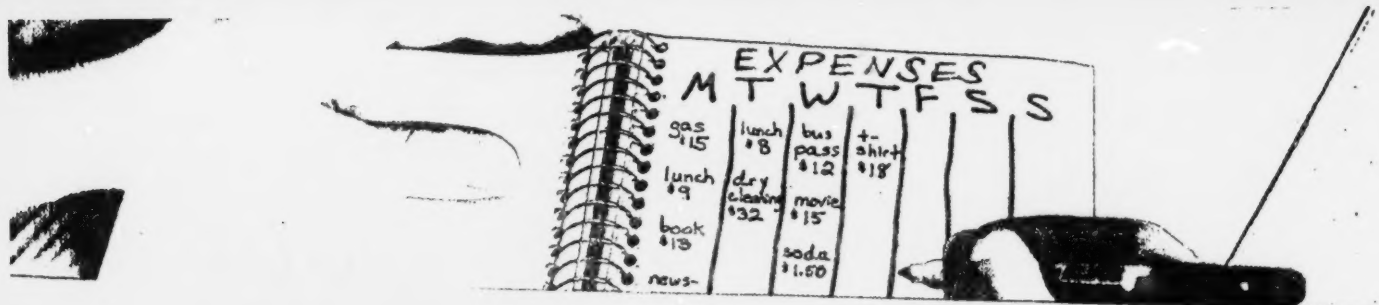
"So many people find it offensive to either seek or accept help. But when you get right down to it, we are a single nation and community. We all pay taxes, and some of those taxes are earmarked for the most vulnerable among us—our kids. When a family has a child with a disability, costs may be way beyond the scope of one family's ability to pay. We shouldn't be embarrassed to do the hard work of finding and applying for the help our children need."

—Diane Hovey, parent advocate,
mother of Sonya, age 13

Costs specifically associated with your child's disability:

Special diet for child with a disability	\$ _____
Medical costs (doctor bills, hospitalization, lab work paid out of pocket)	\$ _____
Co-payment for medical insurance other than Medicaid or Medicare	\$ _____
Therapy (occupational, physical, etc.)	\$ _____
Transportation to/from special care or hospitalization	\$ _____
Lodging and meals during treatment away from home	\$ _____
Costs for disability-related adaptations for a vehicle	\$ _____
Other assistive technology	\$ _____
Disability-related home renovation	\$ _____
Child care/nursing care	\$ _____
Assistance for daily living	\$ _____
Legal fees	\$ _____
Other associated costs related to disability	\$ _____
Other: _____	\$ _____
Other: _____	\$ _____
Other: _____	\$ _____
Total Expenses:	\$ _____





STEP 3: Compare Income and Expenses

Write down your total monthly income (from step 1 on page 12) \$ _____

Write down your total monthly expenses (from step 2 on page 14) \$ _____

Subtract your expenses from your income and list the amount here \$ _____

STEP 4: Find Resources and Make Changes

If you have a private health care plan, it should pick up the majority of your child's medical costs. If you must pay a small portion of the expenses, for example 10 percent, the costs can be very high. (The next chapter covers how to make your medical insurance work for your family, what to do if your coverage is less than adequate, and what to do if you do not have insurance coverage.)

The "associated" expenses to your family's particular situation often are not covered by insurance. For example, as a child with a hearing impairment grows and changes, you will need to purchase new hearing aids. Frequently, these costs are beyond the ability of a family to deal with on its own. Funding resources sometimes do exist, yet there is no single source to provide for these needs. Each child and each family is different and has different needs. This means that you as a parent must take the initiative in seeking out funding resources. Your state's parent center is there to help you find resources as well as moral and emotional support. PACER Center, listed in Chapter 4: Resources, can assist you with finding your state's parent center.

Let us assume for the moment that you have found resources to help you meet some of these associated costs. At the end of the month, do you have money left over to save? Can you start to meet other goals, such as saving for your child's education, investing for your retirement, and establishing an estate for your heirs? If so, you are in good shape. If not, look carefully at how you spend your money on normal cost-of-living items. Now that you know your living expenses, it will be easier to see ways to save. Here is a short list of some ways to help you save money on everyday cost-of-living items:

- △ Make a grocery list from a planned menu and stick to it
- △ Buy store brands, compare prices, and look for the weekly store specials
- △ Clip coupons and use a store "membership" card
- △ Shop the sales and stock up on items you use regularly
- △ Learn new recipes that have simple, readily available ingredients

Manage Debt

When parents are busy providing for a family and are feeling overwhelmed with daily tasks, it is easy to slip into debt especially if they do not have time to investigate funding options. Sometimes, it seems that the only thing to do is to delay paying bills. There is a better way—one that can protect your credit record and help you get back on track to meet your important financial goals.

Get Help

The key is to pay *something* on every bill, and to pay it on time. Along with the payment, send a letter explaining your circumstances, and, if possible, stating when you will pay more. It is a good idea to call and establish personal contact with the customer service manager of the company to which you owe money. Ask about your payment options. More often than not, creditors will work with you to establish reasonable payment plans. Be sure to call *before* you miss a payment.

If doing this yourself is too time-consuming and burdensome at this point in your life, you may want to get expert help. Consider going to a nonprofit credit counseling organization. Acting as a go-between, the credit counseling organization can work with you and those you owe to set up a repayment plan. All bills are consolidated into one payment that you make to the credit counseling organization, which in turn sends the money to those you owe. Usually the service is free or very low cost.



Legitimate, nonprofit, community-based credit counseling organizations provide a much-needed service to people who are having credit problems. *Don't confuse these organizations with so-called credit-repair companies that offer to fix your credit history for a fee.* It can't be done. Promises such as, "We can erase your bad credit, 100 percent guaranteed" are not true. To check out a company's reputation, call the Better Business Bureau (listed in the business pages of the telephone directory) or your state's attorney general's office of consumer affairs or consumer protection (listed in the government pages of the telephone directory).

How else can you take control of your credit rating and manage your debt? In addition to paying your bills on time every month, there are several other things you can do.

▲ **Pay loans and current utility bills first.** Missed payments will hurt your credit rating.

▲ **Use your credit card only for emergencies, and, if possible, pay off the balance every month.** Carrying a balance every month can quickly lead to serious debt.

▲ **If it is not possible to pay off the balance each month, try to pay more than the minimum due.** Interest charges carried over on the unpaid balance cause your debt to grow.

▲ **Charge less than the maximum amount available on your card.** Even if you make the payments on time, creditors may think that you are in too much debt.

▲ **Apply only for the credit you need.** Every time you apply for credit, it appears on your credit report. Creditors may be concerned that you are using too much credit.

▲ **Choose a card with a low interest rate and no (or a very low) annual fee.** A single point of interest can make a huge difference if you end up carrying a large balance.

▲ **Use your credit card to establish good credit.** To do this, pay the card off every month or keep the balance low.

▲ **Keep track of bills and past due notices.** Your debt has not disappeared just because you have stopped receiving notices. The bill may have been turned over to a collection agency and will show up on your credit report. If you cannot pay the bill, communicate and negotiate with the creditor. Make sure that you record all communications with creditors and counseling agents.

About Bankruptcy, Foreclosure, and Repossession

Some parents find that raising a child with a disability consumes all their time and energy. If they haven't taken the time to pay attention to routine tasks, such as paying bills, they may slip into financial trouble. Bills that stack up, cancellation notices from insurance companies, and other correspondence that has not been read will *not* go away. If you have not paid a loan, had a car repossessed, had a house foreclosed on, or have declared bankruptcy, that fact will have a major effect on your ability to obtain new credit. Information about a foreclosure or repossession can stay on your credit report for seven years. A bankruptcy can stay on your credit report for up to 10 years.

KEEP AN EYE ON YOUR CREDIT REPORT

A credit report is a record of how you have paid your bills, credit card debt, and other loans. A credit report shows how much debt you have, if you have made payments on time, and if you have not paid back some loans at all. Credit reports are compiled by national credit-reporting agencies. The typical credit report includes four types of information: identifying information, credit information, public record information, and inquiries.

It's a good idea to order your credit report once a year to make sure there are no errors in it. If errors do appear, you have the right to have the mistakes corrected at no charge to you. The credit report itself will provide information on how to correct errors. If the credit-reporting agency refuses to correct information you believe is in error, you have the right to insert your written explanation into the report. Inquire at your state's attorney general's office or a credit-counseling agency for assistance.

You can order your credit report from any of the major credit reporting agencies listed below. When you order your report, have ready your Social Security number, date of birth, current and previous addresses for the past five years, and maiden name, if applicable.

Equifax

800-685-1111, toll free
www.equifax.com

Experian

888-397-3742, toll free
www.experian.com

Trans Union Corporation

800-916-8800, toll free
www.transunion.com

You may have to pay a small fee (about \$8) to obtain your credit report. Some states have a law that requires credit-reporting agencies to provide you with one or two free copies of your credit report every year. To find out if your state has such a law, contact your state's attorney general's office. If you have been turned down for credit, you can receive free credit reports within a specified time, usually 60 days.

SIMPLE PLEASURES

FOR THE WHOLE FAMILY

- ▲ Find shapes in the clouds.
- ▲ Start a dinner tradition by having each family member tell everyone what he or she is most thankful for each day.
- ▲ Watch or play a sport.

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Insurance

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Health, life, and disability insurance policies are intended to provide you and your family with protection from catastrophic expenses and losses. As you know, health coverage is one of the most important benefits you can have from your employer. The self-employed often can find coverage through industry or professional associations. Others choose individual policies (if they can afford them).

Your Medical Policy

For your medical coverage to work well for your child, it is essential that you understand your policy. The policy explains what benefits are covered and are not covered, the insurance company's obligations, your obligations, and how to appeal if a claim is denied.

Of course, parents do not automatically have an expert's knowledge of medical coverage. Do not expect that of yourself. With an understanding of the basics, however, you will be able to ask the right questions. Begin by identifying types of medical coverage.



Health Maintenance Organization (HMO). Under this type of plan, you must use doctors employed by and hospitals affiliated with the HMO. Also, you must get permission from your primary care doctor to see specialists. Your total cost for each doctor's visit is usually limited to a small co-payment (typically \$10-\$20) and your doctor usually submits paperwork to the HMO for you. HMOs typically offer coverage for preventive care services.



Preferred Provider Organization (PPO). This type of plan has a network of providers from which you may choose and there is usually a small co-payment for each visit to a network provider. You often have the option to see out-of-network providers, but you will have to pay more than if you see a network provider. You may not need a referral from your primary care physician to see a specialist if the specialist is also in the network. PPOs typically provide some coverage for preventive care.

Point-of-Service Plan. This type of plan is the most flexible of all. It has provisions similar to the HMOs, PPOs, and Indemnity Plans (described next). Much like an HMO, the lowest out-of-pocket costs come if you use specific participating providers. The next lowest out-of-pocket costs come from using listed providers, similar to a PPO. The highest out-of-pocket costs come from using providers that are not affiliated with the plan at all. The name says it all—the point, or place, where you receive the service affects your out-of-pocket cost.

Indemnity Plan. Under a traditional indemnity, or fee for service plan, you can go to any doctor you choose and you don't have to get a referral to see specialists. However, these plans are often more expensive than the other types of plans discussed previously. Indemnity plans usually pay only for medical expenses related to illness and accident and not for preventive care. Also, you will have to pay a deductible, an amount that you pay before the plan will pay any claims. Even after the deductible has been met, you may have to pay a portion of the expenses (often an 80/20 split, with the insurance company paying 80 percent of the expenses and you paying 20 percent). Unlike other types of plans, you may be required to pay for services up front and then submit the bill to the insurer for reimbursement.

Exclusive Provider Organization (EPO). An EPO generally operates like an HMO, but the providers are not employees of the EPO. An insurance company generally manages an EPO while an HMO is a business unto itself.

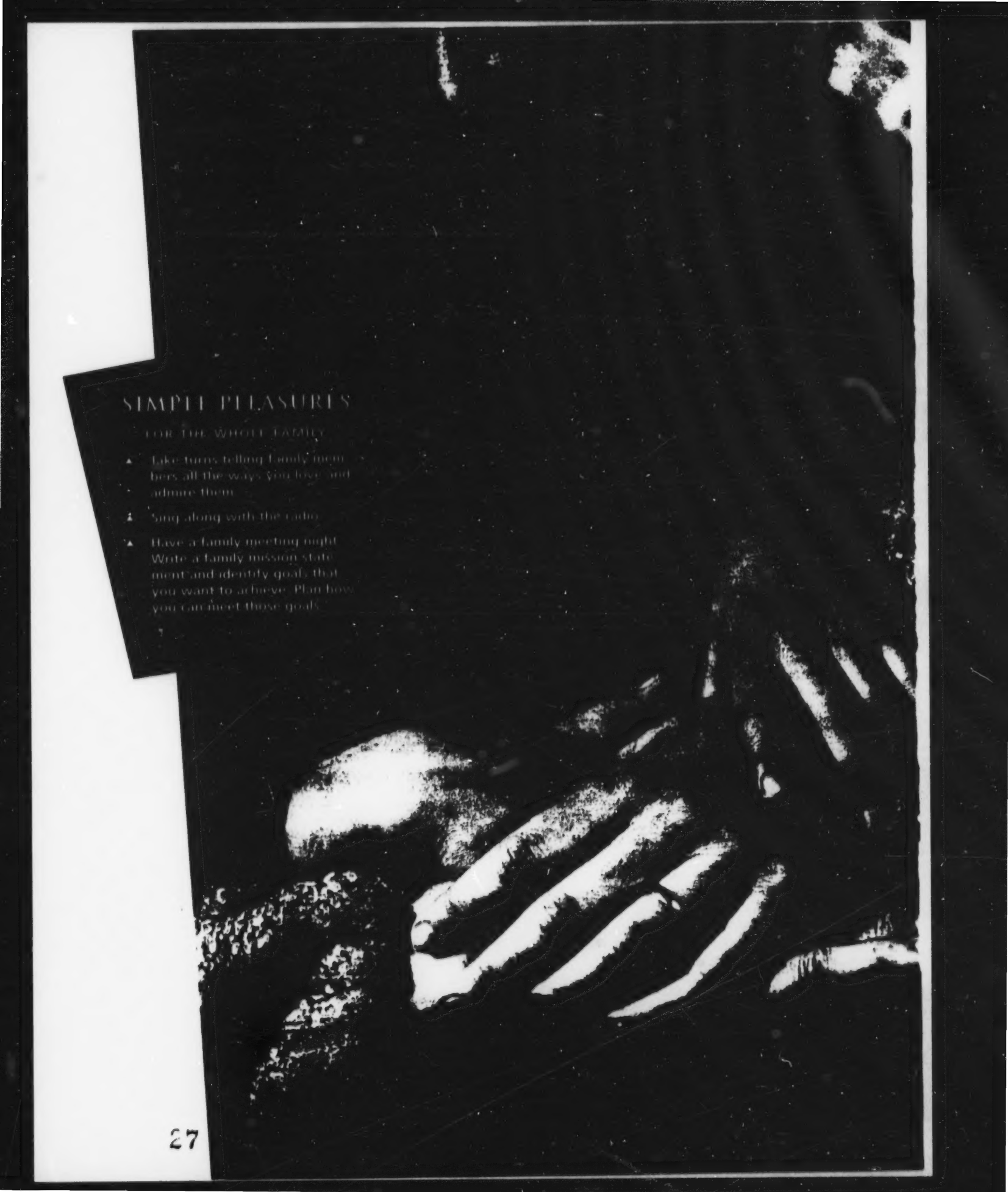
Don't be confused if your plan doesn't operate exactly according to the above explanations. Many plans are designed as variations of the straightforward plans.

Things to Think About

Because your family's situation is special, you need to think carefully about the coverage your plan provides. Are there any provisions for mental health care, emotional behavioral disorders, or other mental disabilities? Even if your health care plan pays for your child's mental or physical health care needs, you may still be subject to a deductible, co-insurance and/or co-payment amount. Factor these costs into your spending plan.

Most importantly, understand the benefits and limitations of your plan as early as possible. Directly ask your insurance agent to clarify these issues:

- ▲ Does my plan allow me to seek out and use the specialists my child needs?
- ▲ Which hospitals can we use?
- ▲ Does my policy cover the type of medicines my child needs?
- ▲ Does my plan cover the specific procedures and therapies my child needs?
- ▲ Does my plan limit the number of times that I can collect per year for a certain item or procedure?
- ▲ Does my policy cover assistive technology?
- ▲ Does my policy cover assessment for mental and physical disorders?
- ▲ If my child has a long-term condition, are there lifetime maximum limits on what my policy will cover?



SIMPLE PLEASURES

FOR THE WHOLE FAMILY

- ▲ Take turns telling family members all the ways you love and admire them.
- ▲ Sing along with the radio.
- ▲ Have a family meeting night. Write a family mission statement and identify goals that you want to achieve. Plan how you can meet those goals.

Here is a chart to help you analyze your policy and learn your benefits:

Medical Plan Features	Good to Above-Average Plans	How My Plan Compares
Specific illnesses or conditions excluded. Is your child's disability covered?	Does not exclude specific disabilities	
Specific treatments excluded or limited. Are there any treatments, such as kidney dialysis, that the policy will not cover?	Few or none	
Hospital costs covered. What share of hospital costs will the policy cover?	All (after deductible, co-insurance and/or co-payment)	
Days of hospital coverage in a year. If your child needs to be hospitalized, how many days will the insurance pay for each year?	All	
Does the policy cover major medical devices? If your child needs life support systems, does the policy pay for them?	All (after deductible, co-insurance and/or co-payment)	
Does the policy cover assistive devices? If the quality of your child's life can be significantly improved with assistive technology, does the policy pay for it?	All (after deductible, co-insurance and/or co-payment)	
Lifetime maximum payment. If your child needs continuing treatment, what is the cap on total payments the policy will make?	\$2 million to unlimited	
Home nursing care. If your child requires frequent or continual nursing care, how much will the policy pay? Is there an exception for custodial care if the child's condition is chronic?	As often or as much as needed (unlimited)	
Annual co-insurance limit. (This has many names. Ask questions so that you understand how it works for your plan.) The co-insurance limit is the cumulative amount of your 10 to 50 percent payments for covered expenses beyond the deductible. How much in total must you chip in on the cost of each provider visit before the policy pays 100 percent of covered charges?	\$2,000	

Medical Plan Features	Good to Above-Average Plans	How My Plan Compares
Co-payment. How much will you pay each time you visit an HMO's or PPO's health care provider?	\$10 to \$20 per visit	
Choice of medical service provider. Can you pick your own doctor, or must you use someone who belongs to the plan's group?	Any provider or a wide choice within a network	
Preexisting condition exclusion period. If this is a new policy, will there be a waiting period before the policy pays for your child's treatment?	None	
Prescription drugs. How much do you have to pay for prescription drugs?	Usually \$10 or \$20 co-payment or plan covers 80 percent of cost (after deductible)	
Mental health counseling. How many outpatient mental health visits will the policy cover in a year?	As many as needed (unlimited)	
Drug/alcohol treatment. What kind of drug and alcohol treatment will the policy pay for?	Rehabilitation (usually limited to in-patient)	
Does the policy cover physical, speech, and occupational therapies? If the quality of your child's life can be significantly improved with the above therapies, does the policy pay for them? Is there a difference in coverage between habilitative and rehabilitative care?	All (after deductible, co-insurance, and/or co-payment)	
Does the policy cover care related to mental health issues? If your child has an emotional or behavioral disorder, obsessive-compulsive disorder, or any other mental disability, are therapy, hospitalization, and prescriptions covered?	All (after deductible, co-insurance, and/or co-payment)	
Covered expenses. Are your plan's "covered expenses" equal to actual charges?	Covered expenses are usual, customary, and reasonable	
Yearly deductible. How much of your own money must you spend on doctor bills before the insurance begins to pay?	\$100 to \$300 per person	

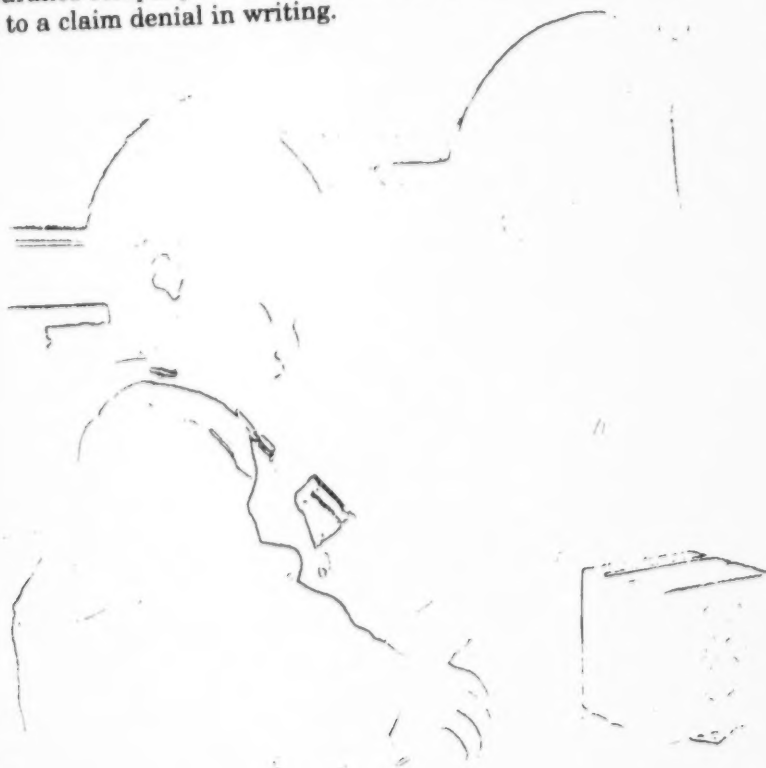
"There is an art to navigating the health care system, and it is one you can learn. Ask for case managers in the hospital and with the insurance company, and then work at developing a good rapport and working relationship. You have to be willing to ask questions and keep on asking questions until you understand. That is your right. It is what you have to do."

—Carolyn Allahouse, parent advocate, mother of Jack, age 15

Making Your Policy Work for Your Child

Obviously, the more your health care plan will help pay for your child's needs, the more money you will save and the less stress you will have from worrying about how to pay the bills. On the surface, it may not seem that you have any control over your coverage—but the opposite is true. Remember, insurance claims processors are attempting to fit your claim to a general rule. It is easy for them to misunderstand the costs and the necessity for various treatments. It is up to you to make your child's case clear so the processor's needs are met. To help with the interaction, follow these tips:

- △ **Ask for one insurance case manager.** This will save you time and help you avoid the frustrating experience of explaining your child's needs over and over again. Send your case manager a picture of your child with a disability, which personalizes your situation, making your child more than a "case."
- △ **If you are denied coverage for a therapy, treatment, or an assistive device that you know your child needs, don't take "no" for an answer.** Insist on the exact reason for the denial. Collect all documentation that explains the need for treatment along with the reason for the denial. Consult your insurance policy for the proper appeals process. Insist that your insurance company or other health care provider supply all information relating to a claim denial in writing.



△ **Keep detailed, written records of everything related to your child's condition.** Keep all bills and insurance claims. These records are essential for figuring tax deductions and for appealing decisions through administrative channels or the court system. You have the right to copies of your child's medical records, so ask for copies of medical records and tests. These records may be helpful for filing appeals and improving your knowledge about your child's health issues.



△ **Appeal decisions that are not in your favor.** Health plans have an appeals process. Ask your health plan provider to send you a copy of its process and use it. Get letters of support from primary doctors and other professionals who are familiar with your child's needs. For example, one mother saw that her child's lab work, which cost many hundreds of dollars a week, was reimbursed at 80 percent for an outside laboratory, but at 100 percent in the hospital. Since a nurse was drawing and submitting the samples and could submit them to the hospital lab, these costs could be covered 100 percent. The insurance review committee decided to cover even the samples previously submitted to a non-hospital lab at 100 percent.

△ **Ask your employer to change the benefits in your company's plan if the current benefits exclude what you need covered.** Self-insured employers are those that pay claims themselves. These employers design their own plans, which means that, to a certain extent, they decide exactly what the covered benefits will be under the plan. Employers that purchase insurance do not have quite as much flexibility as self-insured employers do, but they do have choices in the plans they purchase. Some parents have been successful in having their employers change their plans to include a previously excluded benefit. You should only do this if you feel comfortable disclosing medical information to your employer. For example, one father negotiated with his employer to provide excellent health coverage for his daughter with Down's syndrome. The employer was willing to make the adjustment, even though the company group policy did not originally specify coverage for Down's syndrome and related health problems.

YOUR RIGHTS UNDER THE FAMILY AND MEDICAL LEAVE ACT AND THE AMERICANS WITH DISABILITIES ACT

The Family and Medical Leave Act requires employers with 50 or more employees to provide up to 12 weeks of unpaid leave in certain situations. A family member caring for a child with a disability can use this type of leave. To qualify, employees must have worked at least 1,250 hours during the 12-month period immediately preceding the date the leave of absence begins. To be covered by the Act, you are required to tell your employer about your child's health needs.

In addition, the Americans with Disabilities Act protects you against possible bias an employer may have regarding your ability to perform your job. An employer may not fire you on the presumption that you will miss work or will be less productive because of responsibilities to your child with a disability¹.

Most employers will try to work with you while you are away and caring for your child. Still, it's a good idea to keep careful records of all talks with the employer or people in the human resources office. Also, keep copies of your performance reviews. Legal assistance is available if you feel you have been treated unfairly at work. For information about protection against job discrimination, call the Equal Employment Opportunity Commission (EEOC). You can locate the nearest office by calling 800-669-4000 or visiting www.eeoc.gov.





Lifetime Maximums

If you are reaching the lifetime maximum on your family's medical plan (often set around \$2 million), you may be able to obtain new insurance. You can avoid having to wait through a preexisting condition exclusion period if the following apply:

- △ You have had medical coverage for 18 months
- △ You have already met a preexisting condition exclusion period
- △ You have not been without health coverage for more than 62 days

Another option might be to change insurance carriers during an open enrollment period if your employer offers health insurance from more than one source. If you change jobs and your new employer has health coverage, your coverage starts over. If you meet the criteria cited previously, you won't be subject to another waiting period. If you don't, you'll likely have to wait a certain length of time before the new plan will pay for your child's preexisting condition. This wait could be as long as a year. Of course, for parents of a child with a severe medical condition, such a wait would be insupportable. The best solutions may be to turn to federal and state programs listed in Chapter 4: Resources, or to special grants from civic, fraternal, and charitable organizations.

HOW FREE ARE PARENTS TO CHANGE JOBS?

If you have had medical coverage with an employer, you may well be covered by the Consolidated Omnibus Budget Reconciliation Act (COBRA). COBRA is a federal law that serves two purposes. First, it can extend your health care coverage for 18 months past the end of your employment. Second, it can help you qualify for a private health care policy. For example, if you stay on COBRA until it runs out, you cannot be turned down to buy a private health care policy. Keep in mind that private policies often do not have the same level of coverage and cost more than a group or COBRA plan. The insurance company cannot make you prove insurability or make you face a preexisting condition exclusion period. You must buy the private policy within 180 days from the date that COBRA runs out. If you obtain group insurance with a new employer, the new employer cannot charge you higher-than-standard prices, even if your child has a long-term health problem.

In addition, some states provide special insurance coverage for children while their parents are seeking insurance coverage after changing jobs or for other reasons. Be sure to check into this possibility in your state. Such a program could free you up considerably, even making it possible for you to accept a position at a small company. For contact information, consult the government programs in Chapter 4: Resources of this booklet.



Inadequate or No Medical Coverage

Today, approximately 43 million Americans do not have group or individual health insurance for the following reasons: they are "uninsurable" due to preexisting conditions; they are between jobs, divorced, or self-employed; they choose not to have it; or they cannot afford it. Many of the uninsured are people of the economic middle-class². In other cases, some families may have medical insurance, but the families' income may not be able to cover the co-payments or their plans may not cover the medical treatments that their children require. What are the options when a person has no insurance coverage or when medical coverage is inadequate? Listed below are some government programs that may help. Consult Chapter 4: Resources for contact information about these and other programs.

Medicaid. Medicaid is a federal program, administered by the states, that covers the cost of some medical care. For your child under 18 years of age to receive Medicaid benefits, your income and assets must be below a certain level.

Medicaid Waiver Programs. Waiver programs are for children with disabilities who would otherwise be ineligible to receive Medicaid benefits because of their parents' income. In addition to medical coverage, waiver programs may cover a number of targeted services and supports. You must qualify before you can sign up for most waiver programs. If you qualify, sign up even if you must add your name to a waiting list. In some states, there is a co-pay based on parent's income.

Medicare. This government program is available to children with certain disabilities, such as chronic renal disease which requires a kidney transplant or maintenance dialysis. These children can get Medicare if they have a parent who is getting Social Security or has worked enough to be covered by Social Security Disability Insurance. Contact Medicare for specific information by calling 800-633-4227 or visiting www.medicare.gov.

"It may not seem possible at first, but it is important to start saving money. It makes life a lot easier, a lot smoother, and a lot freer. There are goals, like higher education or opportunities within the community, that are not automatically covered by government programs."

—Deborah Leuchovius, parent advocate, mother of Frederick, age 16

State Children's Health Insurance Program (CHIP).

This program is administered through the states, which set eligibility and coverage, following broad federal guidelines. Recipients must have low incomes, be ineligible for Medicaid, and be uninsured. State programs differ, but all must offer at least these services: in-patient and out-patient hospital services, doctors' surgical and medical services, lab and X-ray services, and well baby/child checkups, including immunizations. Some states may provide additional benefits. CHIP is not yet available in all states. You can apply for CHIP benefits for your child at state public health departments, state social service agencies, or state welfare agencies. In some states, you can apply through the public schools.



Children with Special Health Care Needs (CSHCN) provision of the Social Security Act. If your child is eligible for Supplemental Security Income (SSI), he or she will also be eligible for CSHCN, a program administered through state health agencies. Although there are differences in services, most CSHCN programs help provide specialized services through arrangements with clinics, private doctor's offices, hospital based out- and in-patient treatment centers, and social services. CSHCN programs are known by a variety of names, including Children's Special Health Services, Children's Medical Services, and Handicapped Children's Program. *Even if your child is not eligible for SSI, a CSHCN program may be able to help you.* Local health departments, social services offices, or hospitals should be able to help you contact your CSHCN program.

State Mandated Insurance Programs. State mandated insurance programs are for those who have been refused health insurance, offered health insurance at a higher-than-standard premium, or offered health insurance with a rider that substantially reduces coverage. The owner of a small business may be able to obtain this type of coverage for an employee who has a child with a disability. It is well worth your time to explore the type of program your state may offer.

Non-Medical Benefits from Social Security Available to Children

with Disabilities. There are several ways a child may be able to claim non-medical benefits from Social Security.

Supplemental Security Income (SSI) benefits are available to children with disabilities, under the age of 18, whose disability is expected to last more than 12 months or result in death and whose parents' income and resources are limited. When your child reaches 18, he or she then becomes eligible for SSI if his or her income and assets meet Social Security guidelines and if his or her disability interferes with employability. If a child qualifies for SSI, he or she will also qualify for Medicaid.

The process of applying for SSI can be lengthy. You will need to document your income and expenses. You will be asked many questions about your child's disability, which you will have to support with medical records and written statements from teachers and others who have known your child over a period of time.

Social Security Disability Insurance (SSDI) benefits are payable to children, under the age of 18, if they have a parent who qualifies for or is collecting Social Security Retirement or Social Security Disability Insurance. If a parent has died, children under the age of 18 may collect dependent SSDI benefits on the parent's record if qualified. These payments are available to all children, regardless of whether the child has a disability. SSDI benefits from a parent's Social Security can continue to be paid into adulthood, if the child has a disability that began prior to age 22.

"You learn a lot over the years. Back when my daughter was first diagnosed, I thought we should pay for everything because we could. I thought 'programs' were for truly needy people. I simply had no idea of the costs we would incur. I wish we had applied for programs we were eligible for in the very beginning."

—Carol Bakies, mother of Sarah, age 18

SIMPLE PLEASURES

FOR THE WHOLE FAMILY

- ▲ Check out books from the library to read together, such as poetry, short stories, or novels.
- ▲ Plan a family board game or card game night. (Games are becoming accessible to more people every day. For example, Scrabble® has a Braille version and many cards come in large print versions that are easy to read.)



THE ISSUE OF MEDICAL PRIVACY

Growth in technology has amplified the need to improve America's privacy laws. Recently the federal government has established regulations to help protect the privacy of medical records. The new regulations, authorized by the Health Insurance Portability and Accountability Act of 1996, went into effect on April 14, 2001 and must be complied with by April 14, 2003. The regulations:

- △ Protect all forms of communication of your medical records including electronic records, paper records, and oral communications.
- △ Stipulate that whichever law, either state or federal, provides more protections will supersede.
- △ Regulate the use and disclosure of medical records by some organizations such as health care providers, health plans, and health care clearinghouses. Other organizations, such as life insurers and workers compensation programs, are not regulated under this law.
- △ Mandate advance written patient consent for disclosure of medical information in a variety of cases.
- △ Insure a patient's right to access his or her medical records.
- △ Provide patients the right to amend medical records if they are inaccurate.

The U.S. Department of Health and Human Services Office for Civil Rights (OCR) will enforce the regulations. Additional information is available through the OCR at 866-627-7748, toll free, 866-788-4989 (TTY), toll free, or www.hhs.gov/ocr/hipaa/.

You should keep a current set of your child's medical records in case of an emergency, for an insurance appeal, or for an application for government assistance. You can also check your child's medical records for accuracy and for a full understanding of his or her condition. Request a copy from all doctors and hospitals that have treated your child. In addition, there are many organizations that compile medical information for consumer use such as the Medical Information Bureau (MIB). Contact MIB at: P.O. Box 105, Essex Station, Boston, MA 02112, 617-426-3660, or www.mib.com. You may be charged a minimum fee (\$8-\$15) for each medical record per request.

Life Insurance

Having a life insurance policy can be very important to your entire family—your spouse, your child with a disability, and your other children. A policy can provide financial security in the case of a parent's death. Life insurance also may help pay the high costs that come with a child's chronic illness or disability. For example, you may be able to use the policy as a basis for a loan or cash settlement. (Your options will depend on the type of insurance you own and your credit rating.) Life insurance also may be used to fund a special needs trust (defined on page 46). You may want to ask a financial planner or insurance agent about this possibility.

Social Security and Life Insurance

If you take into account your Social Security benefits, the amount of life insurance you actually need is reduced. When you calculate how much life insurance you will need, take into account these facts:

- △ A surviving spouse can collect the deceased's full monthly Social Security retirement benefits at age 65 to 67, depending on her or his year of birth, and reduced benefits as early as age 60.
- △ A widow or widower who has a disability can collect benefits as early as age 50, or at any age if a child under the age of 16 lives at home.
- △ Unmarried children may collect benefits if they are: under age 18; under 19, but still in school; or over 18, but severely disabled (SSI) and the disability occurred before age 22 (Medicaid).
- △ Social Security may also pay a small death benefit to the surviving spouse or children.

Calculate Your Life Insurance Needs

How much life insurance do parents need? This depends on (1) how much money will be needed after your death to meet your immediate obligations; and (2) how much future income will be required to sustain the household, including the needs of your child with a disability.

The first amount is the sum of final expenses (including uncovered medical expenses, funeral expenses, and final estate-settlement costs) and other obligations (such as outstanding debts, mortgage balance, and college costs). The second sum involves calculating the present value of monies your family will need in the future. A trusted financial advisor can help you determine your future needs.

Your Disability Insurance

Disability insurance is designed to protect the income stream of a parent in case of an accident or illness. There are two types of disability insurance: short-term and long-term. Both types typically replace between 50 to 70 percent of the income lost by a wage earner because of a disability.

Short-term disability insurance typically lasts 90 days to two years. Long-term disability insurance usually starts 30 to 180 days after the onset of a disability. Both are almost always obtained through a job. Depending on the policy, disability benefits may replace income for a period of a few years to, in rare cases, the life of the insured.

If a person is covered by short- and long-term disability insurance, the short-term plan usually stops when the long-term plan starts. The policy also may pay for a rehabilitation program or training for a new job if it appears the disabled person can someday return to work.

Defining "disability" tends to be the stickiest point of these policies. The first step is to read the policy carefully. Some policies pay benefits only if the person is totally disabled: in other words, the person cannot perform *any* work in *any* field. Other policies pay benefits if the victim can't perform the duties of his or her "own occupation." Some allow you to work part time and still receive reduced benefits. If you do not understand your policy, ask the company that issued your policy.

If disability benefits are received from other sources, such as Social Security, worker's compensation, veteran's benefits, and so on, the amount received from employer-provided disability insurance and some personally owned policies may be reduced. Generally, the sum of all disability payments will not exceed 80 percent of a worker's average earnings before the accident or illness.





CHAPTER 3:

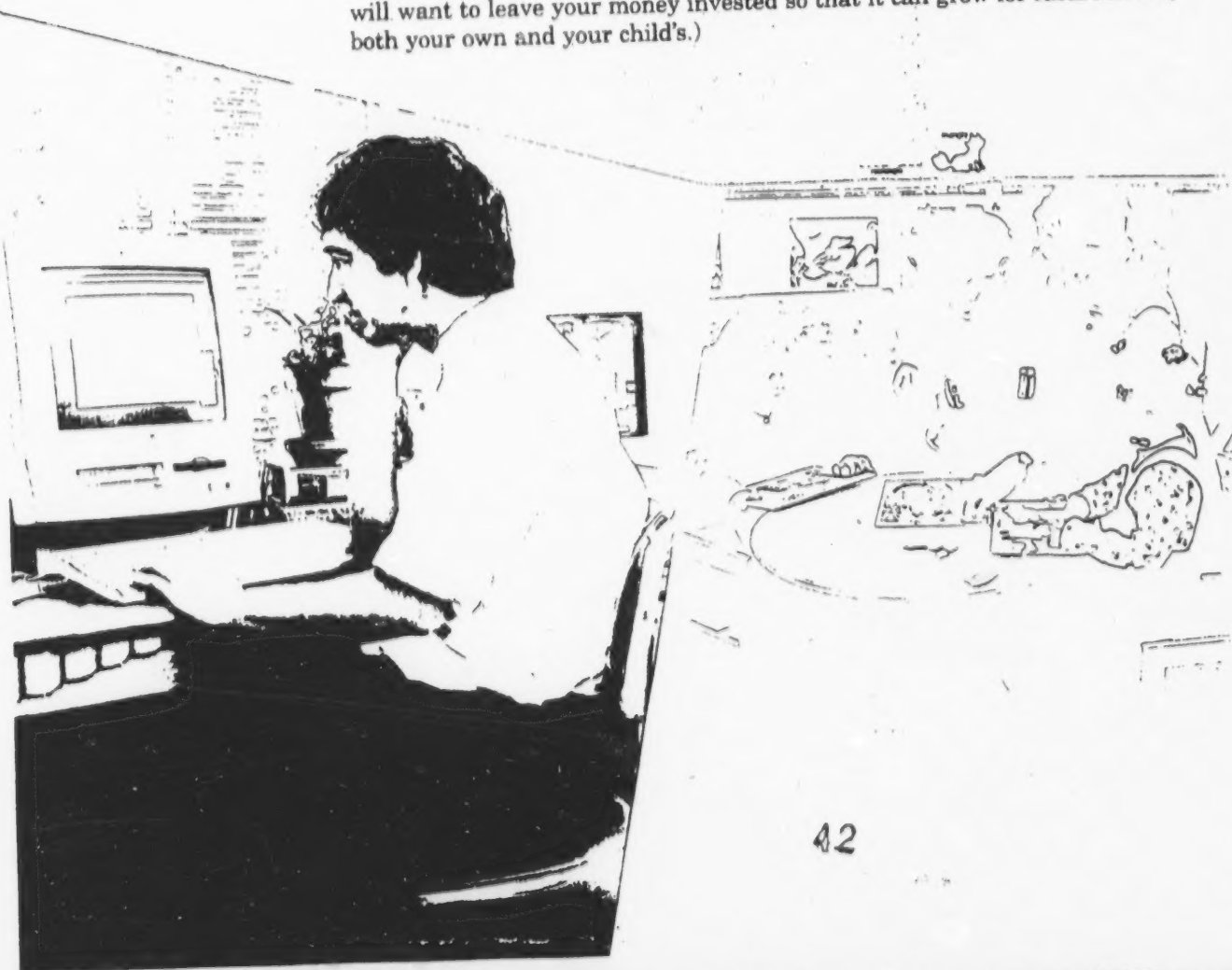
Planning

Your Future and Your Child's Future

W

With so much to think about regarding your child's health and well-being, planning your own retirement may seem secondary or a long way off. But if you don't plan for your future, you can't plan for your child's future. It's like the airline instruction to put your own oxygen mask on before putting one on your child—so you can function to help the child. By planning for your financial future, you will be better positioned to help your child. With special legal arrangements, you may be able to leave funds in a retirement account for your child.

In addition, retirement savings can be used as a safety net for present needs. If necessary, you may be able to borrow from your pension or profit-sharing plan at work. Ask your employer or plan administrator for more information about plan loans. However, it will be necessary to pay off the loans fairly soon to avoid adverse income tax consequences and to rebuild your account. Some types of retirement accounts have more flexible rules regarding borrowing or withdrawing money for medical purposes. (Of course, as much as possible, you will want to leave your money invested so that it can grow for future needs, both your own and your child's.)



Retirement and Savings Programs

Take a look at all the options for saving for retirement, from Social Security to 401(k) plans to your own investments. Understanding all the resources to which you have access will inspire you to start or continue saving.

Social Security

Social Security will provide a part of the money you need to retire—but only a part. It was never intended as the complete answer to retirement for older Americans. For planning purposes, however, you need to know the amount you may receive when you retire. You also need to make sure your Social Security records are correct. To check your Social Security records, complete a copy of the Social Security Statement, Form SSA-7004, and mail it in. To obtain the form, call 800-772-1213 or print a copy from www.ssa.gov. You can also request your Social Security Statement records online from www.ssa.gov. A reply may take up to six weeks. If your records are not correct, the statement will tell you how to make the correction.



Employer Plans

In years past, many companies paid the costs of pension plans for their workers under a program called a "defined benefit plan." A defined benefit plan pays you a fixed amount each month during retirement with the amount depending on how long you worked for the company and how much you earned before you retired.



More likely, your company will offer a "defined contribution" plan instead. In this type of plan, the employer puts a certain amount of money into the plan. Instead of offering a fixed amount to you each month during retirement, the amount you get depends on how much the money in your account grows while invested.

Some types of company-sponsored plans allow employees to contribute their own money to a retirement plan. These plans are the 401(k), 403(b), and SIMPLE plans described in this section. Very frequently, under these plans, the company will match the employees' contributions. Some of these plans allow you, the employee, to contribute to the plan *before* taxes. In other words, you reduce your paycheck to contribute to the plan and therefore reduce your current taxes. Usually, the company administers the plan, but gives you a choice of investments, such as money market funds, mutual funds, annuities, or company stock.

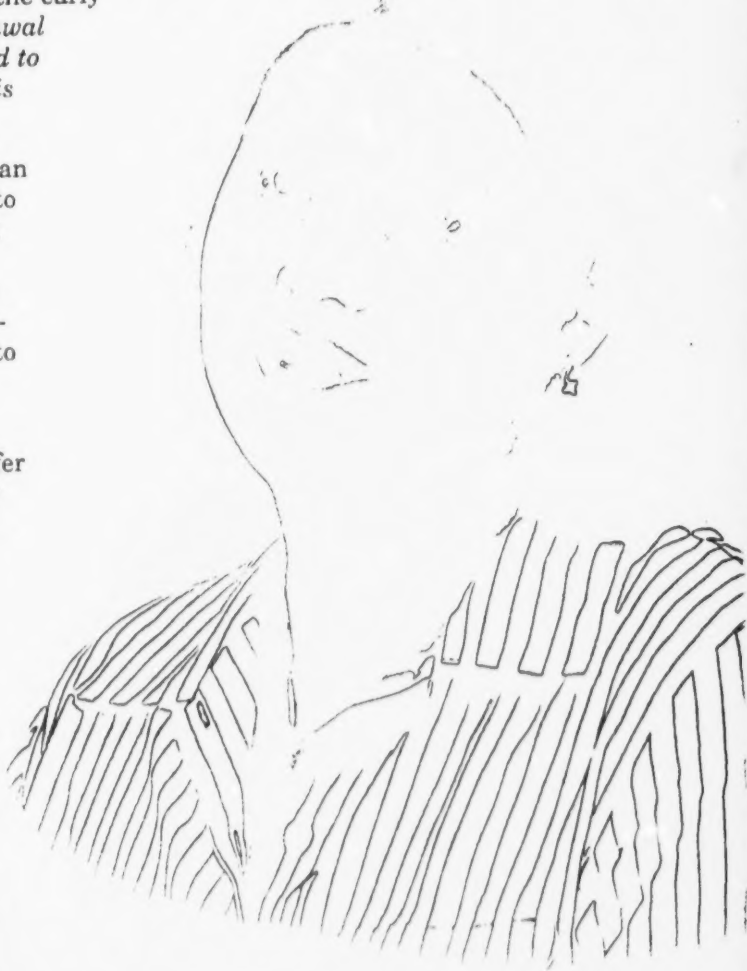
Most retirement plans impose stiff penalties for early withdrawal. If you must withdraw money either to live on or to pay medical expenses, it could be expensive. However, there are some plans that offer flexibility, should you need to make an early withdrawal because of heavy expenses related to your child's disability.

401(k) Plans (403(b) Plans for Nonprofit Organizations). These plans enable you to save for retirement with before-tax contributions. (You pay taxes on the money only after you take it out of the plan—usually after you retire and are in a lower income-tax bracket.) Many employers sweeten the pot by matching the amount you contribute.

You may be able to take a hardship withdrawal from your 401(k) plan, an important feature when you have high medical expenses and may need to use your savings. Keep in mind that hardship withdrawals slow down your money's growth and can be costly because of taxes and the early withdrawal penalty. *However, the early withdrawal penalty does not apply if the distribution is used to pay certain tax-deductible medical expenses or is taken on or after you reach age 59½.*

SIMPLE Plan. A "Savings Incentive Match Plan for Employees," or SIMPLE plan, enables you to contribute as much as \$6,000 a year before tax dollars to a retirement account. Also, your employer must contribute a certain amount to your account. You are vested right away, meaning that your employer's contribution belongs to you right away. There are penalties for early withdrawal.

Profit-Sharing Plans. Your employer may offer to share profits, often by contributing company stock or cash into a tax-deferred account, which means you do not pay any taxes until the money is withdrawn. If the company's stock goes down, so will the value of your profit-sharing bonus. In addition, the company does not have to share profits year after year—so think of your profit-sharing plan as a bonus rather than as a resource for your own retirement or for your child's needs.



Self-Funded Retirement Plans

Saving on your own is not as easy nor as effective as saving through a plan provided by an employer, but you can do it. Keep in mind that the contribution amounts and the rules governing self-funded retirement plans change over time. Ask about or read the rules and penalties before investing in one of the following plans:

Individual Retirement Account (IRA). An IRA is a way to save money for retirement and get a tax break. You can put away as much as \$2,000 a year if you are single and \$4,000 a year if you are married—and this money can be deducted from your taxable income. The earnings are not taxed until money is withdrawn after you retire. You can begin withdrawing funds at age 59½ without penalty.

Roth IRA. You will pay taxes on the money you put into a Roth IRA. But you can take out the money you put into the Roth IRA at any time without paying additional taxes or a penalty. However, if you take out the *interest* that the account earns, you will pay taxes and perhaps a penalty if you are younger than 59½. The amount of money you can put into a Roth IRA is the same as a traditional IRA—up to \$2,000 a year if you are single and \$4,000 if you are married.





Personal Investments and Savings. When you invest on your own for retirement, your money will not grow as fast as it would in a tax-deferred plan, such as a 401(k), an IRA, and others described here. Still, investing on your own for retirement is better than not investing at all. Most financial advisors suggest that you invest money in stocks, bonds, or mutual funds. These are long-term investments suitable for retirement because they have the potential to grow over time.

Your Long-Term Care

Long-term care for aging parents—such as a nursing home, an assisted living facility, home health care—can cost a great deal. You cannot predict exactly what kind of care you might need in the future, or know exactly what the costs will be. But since you would pay such expenses out-of-pocket, you may want to consider adding long-term care insurance to your retirement planning. Medicare does not cover long-term care, and Medicaid provides coverage only for retirees whose funds and assets qualify them as “poor” according to government guidelines.

Purchasing long-term care coverage helps ensure that you can retain your assets for your own retirement, for your heirs, or to fund a special needs trust for your child with a disability. The cost depends on your age, the level of benefits, the maximum benefit period, and the length of time you are willing to wait until benefits begin. Coverage can extend to care in a nursing home or assisted living facility as well as to home health care. As with any type of insurance, it will be necessary to read the policy carefully and to compare it with others before purchasing. Under certain circumstances, a portion of the premium may be deductible from your income when calculating your taxes.

Estate Planning for Your Family

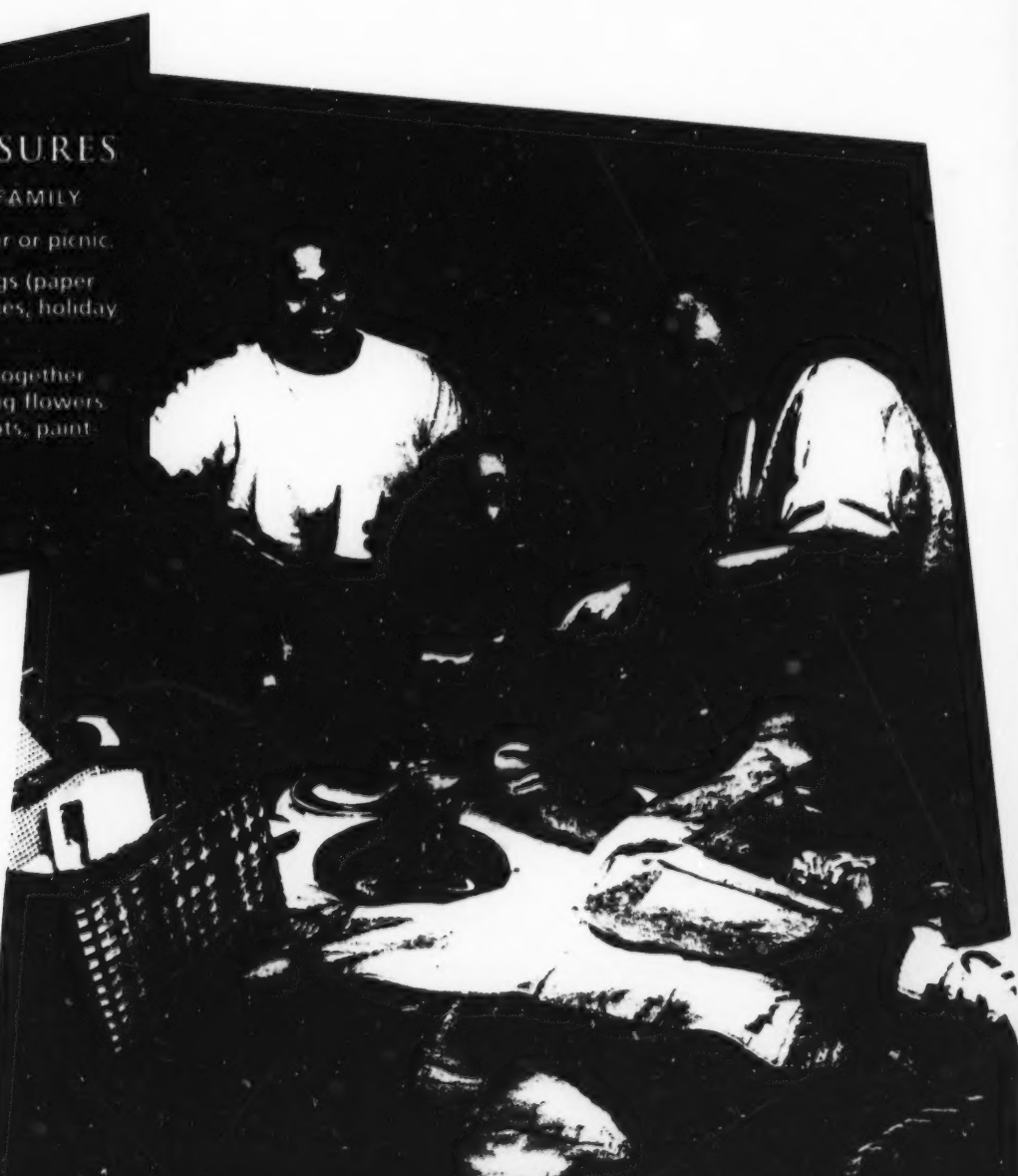
Families who have a child with a disability need to plan very carefully so that family assets can be used in the child's and other family members' best interests. Proper planning will enable your child to "receive his or her inheritance," yet still qualify for or retain Supplemental Security Income (SSI), Medicaid, and other government benefits. Loss of these and related government programs could create a tremendous hardship. Yet these government

SIMPLE PLEASURES

FOR THE WHOLE FAMILY

- ▲ Plan a family dinner or picnic.
- ▲ Color or draw things (paper bags for sack lunches, holiday decorations, etc.).
- ▲ Do home projects together (yard work, planting flowers or vegetables in pots, painting, etc.).

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programs were never intended to offer more than a subsistence level of income. Careful planning will enable you to provide other needed resources. With proper legal and financial planning, parents can ensure that the person with the disability will have a good quality of life.

An Overview of Estate Planning

There are two categories of assets to consider when planning your estate: (1) probate assets, such as those that would be listed in and controlled by your will; and (2) non-probate assets, such as life insurance or proceeds from an Individual Retirement Account (IRA) among others, which transfer according to the terms of the contract and not by the terms of your will. Check with a financial planner or an attorney for more information.

In both cases, so as not to jeopardize government benefits, it is important not to name the person with a disability as an outright heir or beneficiary. You can take one of three routes listed below to accomplish this:

- △ Simply omit the person with a disability from the will. In some states you must state clearly that it is your intent that the person in question (when she or he is your daughter or son) not receive an inheritance from you. The statement of omission is sometimes accompanied by the next items.
- △ Make a specific gift to an individual (other than the person with a disability) with an informal and unenforceable understanding that the proceeds are to be used for the person with a disability. This cannot be a commitment on the part of the named recipient. If it were a commitment, the gift in question would be considered an asset of the person with a disability and jeopardize his or her public assistance. The informal nature of this agreement means that there are no guarantees that the gift will be used for the benefit of the person with a disability.
- △ Establish a special needs trust and have the child's share of your assets paid into this trust.

The Special Needs Trust

This trust, also called a "supplemental care trust," receives and manages money for the benefit of your child with a disability. To be sure that needed government assistance continues the trust *must* be set up correctly. The trust money may not be used for food, shelter, and clothing; it can be used for items *not* paid for by government assistance such as medical expenses, dental work, home repair, or education. Make sure to only use a lawyer who has extensive experience with these trusts. A minor error can create a lifetime of problems.

The trust can receive inheritances or gifts. By contributing to the trust, *friends and family members can help your child without the concern of jeopardizing government benefits.* Money inside the trust can be invested and earn money with no limits. The assets and earnings belong to the trust and not the child. Parents can establish and fund the trust, and act as trustees while they are alive, or the trust can be written so that it is established by the parents' will and starts to function after the parents' death. There are numerous advantages to establishing a trust now, even before your child reaches age 18. Ask your lawyer about these advantages.



"I feel better knowing that my family will have enough money to take care of themselves in case something should happen to me. Saving for my retirement and for my family's future is just as important to me as budgeting for the mortgage, groceries, and medication. I contribute to an employee retirement plan and have an annuity for my own security. For my family, I have a term life insurance policy and a pre-paid college fund for both my children. Also, I take every opportunity I get to teach my daughter about spending within her means. I plan to continue that with my son as soon as he gets old enough to spend a dime."

—Chris Stevens, father of Ali, age 7, and Jacob, age 1

SIMPLE PLEASURES

FOR THE WHOLE FAMILY

- ▲ Learn to play a musical instrument.
- ▲ Have a movie night. Rent videos or check the newspaper for movies on television and make your own snacks.
- ▲ Watch the sun rise and/or set.



Fund a Special Needs Trust

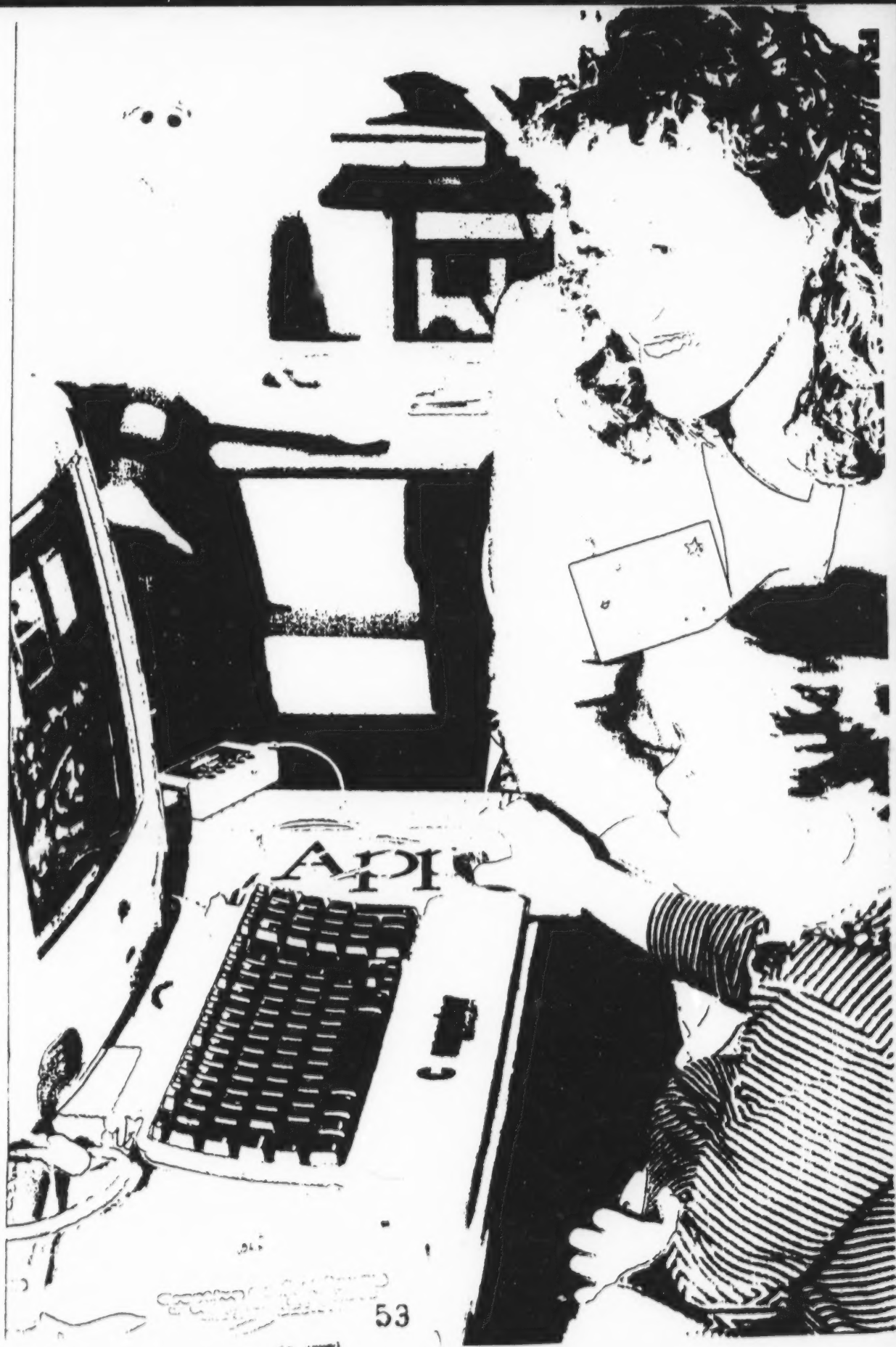
Many families believe there is very little money or assets to put into a special needs trust. This is seldom true. You may have more assets than you realize, although some may become available only after your death. Your financial planner can provide major help in analyzing your finances and finding the resources to put into the trust. Some possibilities include³:

- △ Insurance, one of the few ways of guaranteeing future funds
- △ Standard government benefits, such as Social Security survivor benefits
- △ Savings and investments, including money in retirement funds
- △ Assistance and inheritances from friends and family members
- △ Property, such as a family home
- △ Military benefits

"Sometimes, you just have to talk to friends and family members who want to help out financially. You have to be sure they understand how to contribute without endangering your child's eligibility for benefits. (Even birthday and holiday gifts of money, if saved over time, can add up and be counted as assets that belong to your child.) I've learned to suggest other ways for family and friends to carry out their kind intentions."

—Donna Halcomb, mother of John, age 16, and Patrick, age 20





Conservatorship (Guardianship)

The question of conservatorship (referred to as guardianship in some states) arises when a child is approaching age 18 and has a disability that results in poor judgment and the inability to make decisions that are in his or her own best interest. Conservatorship is an arrangement in which the parent(s) or other responsible adult(s), is given the legal right to make decisions for the person with a disability. Conservatorship is a court-appointed role.



A conservatorship may be "of the person" or "of the estate." A conservatorship of the person enables the guardian to make all necessary decisions in areas such as shelter, clothing, medical care, food, contracts the ward may wish to make, and so on. A conservatorship of the estate, on the other hand, entails overseeing and managing assets. It involves keeping careful financial records. It may be preferable to use a special needs trust rather than a conservatorship of the estate. As a parent, you have probably been fulfilling these roles while your child was under the age of 18. You will probably want to continue in these roles.

If a conservatorship is appropriate for your child, then it is also important to have yourself named as "representative payee," although someone other than a parent can be the representative payee. As representative payee, you will control the Social Security funds and maintain your child's financial records showing, for example, that SSI benefits are spent in the categories of food, shelter, and clothing. You do not have to go to court to establish yourself as representative payee.

The difficulty comes when you must ask someone else to succeed you in the role of conservatorship of your child, which you must do when you write your will. It may be troubling to ask others to take on this responsibility, yet it must be done. In fact, after a successor has been named, parents often have a feeling of great relief. If you are delegating these roles in your will, make certain that the person or persons appointed understand their responsibilities and willingly accept them.⁴

CHAPTER 4:

Resources

R

Resources that can help you raise your child with a disability change continually, and different states provide different services, so the list in this section is not exhaustive. However, this list does provide the keys to the various areas into which you will want to look. Once you have started building resources for your child, you will discover more as you go along.

Parent Organizations

Parent Advocacy Coalition for Educational Rights (PACER Center)
Minnesota's federally funded parent center and the national coordinating office for the network of 100 federally funded parent training and information centers. Hmong and Spanish language advocates and translations available. www.pacer.org; www.taalliance.org; www.fape.org; 952-838-9000; 952-838-0190, TTY; 888-248-0822, toll free.

Family Voices

Clearinghouse for information and education; works with policymakers to provide family perspective on health issues: www.familyvoices.org; 888-835-5669, toll free.

SIMPLE PLEASURES

FOR THE WHOLE FAMILY

- ▲ Set up a birdfeeder or visit an outdoor site to bird watch.
- ▲ Start a therapeutic hobby such as painting or molding clay.
- ▲ Gaze at the stars or use a telescope to search for and learn about specific constellations.





Comprehensive Information/ Referral Centers

National Information Center for Children and Youth with Disabilities (NICHCY)

Focus is on children and youth (birth to age 22); information and referrals include planning and financial issues relating to disability; services available in Spanish: www.nichcy.org; 800-695-0285, toll free.

Exceptional Parent Magazine

Publishes a comprehensive annual directory of resources; monthly magazine includes articles on financial planning: www.eparent.com; 877-372-7368, toll free.



Find a Financial Planner or Lawyer

National Guardianship Association

Provides educational training and network opportunities for guardians:
www.guardianship.org; 520-881-6561; 520-326-2467, TDD.

The Arc of the United States

May be able to recommend attorneys and/or financial planners; publishes state-specific guides for estate planning; offers guardianship or master trust programs: www.thearc.org; 301-565-3842.

Your Rights as a Caregiver

National Family and Caregivers Alliance

Provides information on the legal rights of caregivers: www.nfcacares.org;
800-896-3650, toll free.

Children's Defense Fund

Provides a voice for all the children of America who cannot vote, lobby, or speak for themselves: www.childrensdefense.org; 202-628-8787.

American Bar Association Commission on Mental and Physical Disability Law

Information on all aspects of the Americans with Disabilities Act, the Family and Medical Leave Act, and related legislation, including your rights as a caregiver: www.abanet.org/disability; 202-662-1570.

Insurance

The Life and Health Insurance Foundation for Education (LIFE)

Nonprofit, industry-sponsored organization; provides information on life, health, and disability insurance; provides links to interactive calculators to help you determine how much insurance you need: www.life-line.org;
202-464-5000.

Consumer Federation of America

Access to actuarial experts who can tell you whether information contained in an insurance policy is adequate for good decision-making: www.consumerfed.org;
202-387-6121.

The Patient Advocacy Coalition

Help with understanding your medical policy; help with making insurance appeals. www.patientadvocacy.net; 303-744-7667, voice/TDD; 877-435-7123, toll free.

The National Committee for Quality Assurance (NCQA)
Evaluates and accredits managed care programs: www.ncqa.org; 202-955-3500.

Government Programs

Social Security Administration

Administers Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), retirement and disability benefits for parents/caregivers, and Insure Kids Now health insurance programs: www.ssa.gov; 800-772-1213, toll free.

Insure Kids Now

Puts families in direct contact with their own state's children's health insurance program: www.insurekidsnow.gov; 877-543-7669, toll free.

Medicaid

Provides comprehensive medical care to those who meet eligibility requirements: www.hcfa.gov/medicaid; 800-633-4227, toll free.

Medicaid Waiver Programs

Expands Medicaid coverage for those who meet eligibility requirements: 800-633-4227, toll free; www.hcfa.gov/pubforms, text of regulations expanding Medicaid; 202-682-0100; medicaid.aphsa.org, state-by-state Medicaid Waiver Program information.



Title V: Children with Special Health Care Needs (CSHCN)

The Institute for Child Health Policy publishes the *Directory of State Title V CSHCN Programs: Eligibility and Scope of Services*: www.ichp.edu; 352-392-5904; 888-433-1851, toll free.

Special State-Chartered Insurance Plans (for wage earners)

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) requires that all states implement policies guaranteeing access by small businesses and "eligible individuals" to health insurance of some kind. ("Eligible individuals" are those considered to be "uninsurable" under other insurance plans.) More than half the states have complied and all are in the process of instituting these special plans. Check with the U. S. Department of Health and Human Services for more information; www.dhhs.gov; 202-619-0257; 877-696-6775, toll free.

Cover "Associated" Costs

Assistive Technology

Every state in the country has established a state program for assistive technology to handle services such as training for new equipment or a loan program for the purchase of the equipment: www.resna.org/taproject; 703-524-6686; 703-524-6639, TTY.

The Alliance for Technology Access (ATA)

One of the nation's largest resources for assistive technology: www.ataccess.org; 415-455-4575.

The Foundation Center

Provide information on a variety of private foundations, including corporate foundations: www.fdncenter.org; 212-620-4230; 800-424-9836, toll free.

Air Life Line

National nonprofit charitable organization that flies ambulatory patients who cannot afford the cost of travel to medical facilities for diagnosis and treatment: www.airlifeline.org; 916-641-7800; 877-247-5433, toll free.

Respite Care

Respite care normally involves someone else taking care of your child for a short time, such as a few hours, a weekend, or more. Medicare Waiver Programs sometimes include respite care. Employers may sometimes provide funding for such care. National Respite Locator Service: www. chtop.com; 919-490-5577.

IN-CLOSING

F

Families raising children with disabilities may think they *cannot* plan their finances. Considering all the medical and other costs you are facing, planning does seem like an uphill battle. Yet the consequence of not planning is increased anxiety.

By looking squarely at both the costs your family is incurring and will incur along with the resources available, you reduce your own stress. You empower yourself. Chances are very good that you will be able to create ways to meet the needs of your child with a disability at the same time you are meeting the needs of other members of your family.

No one expects you to put your entire financial house in order all at once. Planning is a rational, methodical, step-by-step process. If you approach it that way—step by step—you can accomplish what you have set out to do. As with any complex task, prioritize by choosing to do basic things first (getting records organized, understanding your insurance policies, etc.). Break the work into manageable segments. Say to yourself, "This week I will call my creditors and pay bills; next week I will begin the search for a financial planner; the following week ..." and so on. It is amazing how much you can accomplish when you plan to work this way.

Your circumstances may not be easy. Only you and other parents who have struggled with finances know how difficult things are. Keep in close contact with those who have gone before you and best understand your situation. When you have taken these steps, you will have a sense of relief and renewed possibility.





ENDNOTES

B

Below are the resources that were used throughout this document.

1. Sue Shellenbarger, "A Little Known Part of the Disabilities Act Protects Caregivers," Wall Street Journal, 23 August 2000.
2. The Journal of Financial Planning, "The Health Coverage Crunch," March 2000, p. 5431.
3. News Digest, "The Special Needs Trust," National Information Center for Children and Youth with Disabilities, Washington, D.C., 6-8.
4. Robert G. Gunderson, attorney at law, "The Conservatorship Process," 2000, Minneapolis, MN.



NOTES

This image shows a single sheet of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There is no handwriting or other markings on the paper.

ACKNOWLEDGMENTS



Parent Advocacy Coalition for Educational Rights (PACER Center)
PACER Center's mission is to improve and expand opportunities that enhance the quality of life for children and young adults with all disabilities and their families. PACER Center is the national coordinating office for the Technical Assistance Alliance for Parent Centers, which provides technical assistance to 100 Parent Training and Information Centers and Community Parent Resource Centers throughout the country. It is also the national coordinating office for the Families and Advocates Partnership for Education, which aims to improve education outcomes for children with disabilities.

PACER Center's programs help parents become informed, effective representatives for their children from early childhood to young adulthood. Contact PACER at: 8161 Normandale Boulevard, Minneapolis, MN 55437; 952-838-9000; 952-838-0190, TTY; 888-248-0822, toll free; www.pacer.org; www.taalliance.org; www.fape.org. Paula Goldberg, *Executive Director*, Mary Schrock, *Development Director*, Willa Hathaway, *PACER Center Project Coordinator*.



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National Endowment for Financial Education (NEFE)
NEFE is an independent, nonprofit foundation committed to educating Americans about personal finance and empowering them to make positive and sound decisions to reach financial goals. The National Endowment for Financial Education, NEFE, and the NEFE logo are federally registered service marks of the National Endowment for Financial Education. For more information about the National Endowment for Financial Education, visit www.nefe.org.

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